



Department of Health  
Developmental Disabilities  
Division



# Neurotrauma Supports

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## *Strategic Plan*

## *Fiscal Years (FY) 2018-2020*

A three-year plan to further the mission of the Neurotrauma Supports program to enhance partnerships that ensure individuals with neurotrauma and their family members have access to effective services and supports.

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# Neurotrauma Supports

## Strategic Plan

### Fiscal Years (FY) 2018-2020

Prepared with support provided by  
Susan L. Vaughn, Director of Public Policy  
National Association of State Head Injury Administrators

Hawai'i State Department of Health  
Developmental Disabilities Division  
Community Resources Branch  
**Neurotrauma Supports**  
3627 Kilauea Avenue, Room 411  
Honolulu, HI 96816

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## Message from the Director of the Department of Health

Aloha,

Since 2002, the Neurotrauma Supports program in the Department of Health, Developmental Disabilities Division has been conducting activities to support individuals with neurotrauma and educate the public on neurotrauma. With the completion of the Neurotrauma Supports Strategic Plan for fiscal years 2018-2020, Neurotrauma Supports and stakeholders have set the goals and direction for continuing to improve the lives of individuals with neurotrauma. The Department of Health stands firmly behind the Developmental Disabilities Division Neurotrauma Supports' mission of ensuring individuals with neurotrauma and their families have access to services and supports.

Neurotrauma, which includes traumatic brain injury, spinal cord injury, and stroke, has gained increasing attention nationwide. The Department of Health will use this Strategic Plan as a vehicle for improved access to services and supports for healthy and meaningful lives for individuals with neurotrauma and their families.

Sincerely,

A handwritten signature in black ink that reads "Virginia Pressler". The signature is written in a cursive, flowing style.

Virginia Pressler, M.D., M.B.A.  
Director Department of Health

## Message from the Developmental Disabilities Division Administrator

The Neurotrauma Supports Strategic Plan for fiscal year 2018-2020 is a dynamic plan which represents the direction the Department of Health Developmental Disabilities Division is taking to address building a more effective and responsive system for people with neurotrauma and their families.

Creating a shared vision, and working to accomplish a common mission has been a fruitful endeavor. The development of this plan has allowed us to revisit our core principles and values and helped us develop a comprehensive set of goals and objectives as we move forward together.

We would like to acknowledge the support we received from the National Association of State Head Injury Administrators, as well as the continuing commitment and efforts of consumers, advocates, community partners, and members of the State Traumatic Brain Injury Advisory Board and the State Neurotrauma Advisory Board.

We extend a special thanks to the dedication and foresight contributed by the Neurotrauma Supports Strategic Planning Committee.

Warmest aloha,

A handwritten signature in blue ink that reads "Mary Brogan". The signature is fluid and cursive, with a long horizontal stroke extending from the end of the name.

Mary Brogan, Administrator  
Developmental Disabilities Division

## Introduction

Traffic accidents, falls, blast injuries, or blood clots are just some of the causes of neurotrauma, which can significantly alter an individual's way of life. A person who has sustained a neurotrauma injury may experience cognitive, sensory, emotional, and/or physical functioning. The injury may alter the individual's ability to perform activities of daily living such as eating, bathing, dressing, walking, and toileting, including challenges with incontinence. Other issues may include the ability to return to work or maintain employment and to sustain relationships with family and friends. Depending on the severity of the neurotrauma, individuals may need short-term or long-term rehabilitation and community services and supports to restore functionality. Individuals may also need to learn compensatory strategies for physical, cognitive, and/or behavioral deficits in an effort to live as independently as possible.

*What is neurotrauma?* In statute, Hawai'i has defined neurotrauma as a severe and chronic disability of a person that is attributable to an injury to the central nervous system, including traumatic brain injury (TBI), spinal cord injury, and is likely to continue indefinitely. The statute states neurotrauma can also include other neurological dysfunctions but does not include substance misuse and abuse, Alzheimer's disease, or the infirmities of aging. Stroke was included in the definition of neurotrauma because it is a preventable neurological dysfunction that can result in substantial functional limitations in the areas described in the statute: self-care; speech, hearing, or communication; learning; mobility; self-direction; capacity for independent living; and economic sufficiency. To address the needs of individuals with neurotrauma, the Hawai'i State Legislature enacted legislation, Act 160, Section 321H-4, Hawai'i Revised Statutes (HRS), to create a Neurotrauma Special Fund (NSF) in 2002. This legislation generates funding pursuant to the surcharges levied under HRS sections 291-11.5 (child passenger restraints), 291-11.6 (mandatory use of seat belts), 291C-12 (accidents involving death or serious bodily injury), 291C-12.5 (accidents involving substantial bodily injury), 291C-12.6 (accidents involving bodily injury), 291C-102 (noncompliance with speed limit), 291C-105 (excessive speeding), and 291E-61 (operating a vehicle under the influence of an intoxicant). The Department of Health's Neurotrauma Supports program, housed in the Developmental Disabilities Division, administers the NSF with advice and recommendations from the Neurotrauma Advisory Board (NTAB), which was also created by Act 160, Section 321H-3, HRS in 2002. The fund is to be used for:



- *Education on neurotrauma;*
- *Assistance to individuals and families to identify and obtain access to services;*
- *Creation of a registry of neurotrauma injuries within the State to identify incidence, prevalence, individual needs, and related information; and*
- *Necessary administrative expenses to carry out this chapter not to exceed two percent of the total amount collected annually.*

The purpose of this Strategic Plan for fiscal years 2018-2020 (July 2017 to June 2020) is to set a course for improving and expanding resources and state capacity to enable individuals with neurotrauma and their families to live healthy and meaningful lives in their home and community of choice.

## Section 1: Executive Summary

The Hawai'i Department of Health (DOH), Developmental Disabilities Division's Neurotrauma Supports program is charged with setting a direction for a comprehensive system to support and offer services to survivors of neurotrauma. The program convened a Strategic Planning Committee in October 2016 to assist the program with identifying goals, objectives and strategies for improving resources and assistance to enable individuals with neurotrauma to return to their home and community in order to live as independently as possible. The committee consisted of survivors of neurotrauma, state staff, and representatives from the Brain Injury Association of Hawai'i (BIA-HI), private medical facilities, the Division of Vocational Rehabilitation, and the Pacific Disabilities Center at the University of Hawai'i. The goals drafted by the Committee were also shared with stakeholders, including the Neurotrauma Advisory Board (NTAB), the State Traumatic Brain Injury Advisory Board (STBIAB), the Brain Injury Association of Hawai'i, families, survivors, and other community stakeholders whom were given opportunities for providing input.

This Strategic Plan builds on the work of the Neurotrauma Supports program by identifying three specific goals and related objectives to pursue over the next three years. These goals may be advanced through partnerships and collaboration with public and private healthcare organizations, social services programs and other organizations that serve individuals with disabilities. The goal of these partnerships are to assist people throughout the community to obtain the necessary training and supports needed to meet the needs of individuals with neurotrauma and their families, as well as identify potential funding resources and services that currently serve individuals with similar disabilities and may potentially be available to individuals impacted by neurotrauma. Goals of this Strategic Plan are:

*Goal 1: Expand public and professional awareness about neurotrauma and service delivery.*

*Goal 2: Increase the state's capacity to identify and disseminate information about resources, services and supports to individuals with neurotrauma and their families.*

*Goal 3: Identify strategies and partnerships to improve access to health care, rehabilitation, community-based long-term services and supports and community integration for individuals with neurotrauma.*



## Section 2: The Strategic Plan: Background and Overview

### *Information and Statistics on Neurotrauma in Hawai'i*

#### **Traumatic Brain Injury (TBI)**

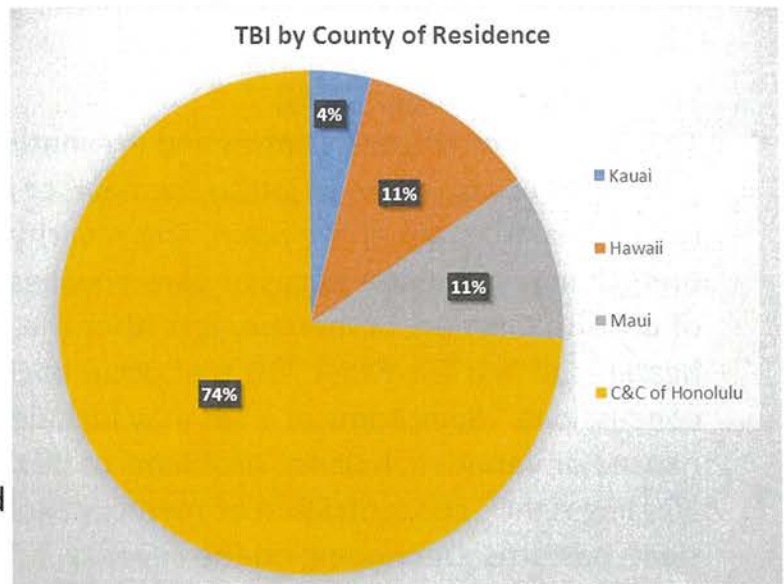
The Centers for Disease Control and Prevention (CDC) defines traumatic brain injury (TBI) as a “bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. The severity of a TBI may range from ‘mild’ (i.e., a brief change in mental status or consciousness) to ‘severe’ (i.e., an extended period of unconsciousness or memory loss after the injury). Not all blows or jolts to the head result in a TBI. Most TBIs that occur each year are mild, commonly called concussions.” Symptoms of a TBI may include headache or pressure in the head, nausea or vomiting, balance problems or dizziness, blurry vision, confusion, not “feeling right”, concentration or memory problems, mood changes, and changes in sleep patterns. Depending on the severity, a TBI may affect long-term cognitive, motor, sensation, and/or emotional functioning (CDC, 2015).

Mirroring national data trends, the Hawai'i Injury Prevention Program reports that unintentional falls were the leading cause of TBI from 2011 to 2015 and accounted for more than half of the nonfatal injuries. Motor vehicle crashes (21%) were the next most common cause for TBI-related hospitalizations, followed by other (12%), homicide (8%), being unintentionally struck by or against something (3%) and suicide (1%). Being unintentionally struck by or against something (20%) was the next most common cause for TBI-related ED visits, followed by other (11%), homicide (10%), and motor vehicle crashes (8%). Residents aged 65 years or older accounted for about half (48%) of the TBI-related hospitalizations and youth under age 15 accounted for almost one third (30%) TBI-related ED visits between 2011 and 2015.

The following data was obtained from the Hawai'i Health Information Corporation (HHIC), a private non-profit organization that collects statewide data on hospitalization and emergency room visits. In 2015, there were 1,657 unique individuals who were hospitalized for a TBI. In addition, there were 3,474 unique individuals who sought treatment for a TBI in an ED in 2015. Each individual was counted once in the total number of hospitalizations or emergency room admissions, even if the individual was hospitalized or admitted to the ED more than once in 2015. Only current residents of in the State of Hawai'i were included in the count. The table

and chart below illustrate the breakdown of TBI hospitalizations in 2015 by County of Residence.

County	Count
Kaua'i	66
Hawai'i	190
Maui	176
City & County of Honolulu	1225
Total Hospitalizations in 2015	1657



Source: HHIC (reflects data collected from 2015).

### Spinal Cord Injury (SCI)

A traumatic spinal cord injury (SCI) may stem from a sudden, traumatic blow to the spine that fractures, dislocates, crushes, or compresses one or more vertebrae. It also may result from a gunshot or knife wound that penetrates and cuts the spinal cord. Additional damage usually occurs over days or weeks because of bleeding, swelling, inflammation and fluid accumulation in and around the spinal cord. Damage to any part of the spinal cord or nerves at the end of the spinal canal can cause permanent changes in an individual's strength, sensation and other body functions below the site of the injury. A non-traumatic spinal cord injury may be caused by arthritis, cancer, inflammation, infections or disk degeneration of the spine.

Symptoms depend on the severity of injury and where the injury takes place on the spinal cord. Individuals with a spinal cord injury may experience partial or complete loss of sensory function or motor control of arms, legs and/or body. The most severe SCI affects the systems that regulate bowel or bladder control, breathing, heart rate and blood pressure. Most people with SCI experience chronic pain (World Health Organization, 2013).

Spinal cord injuries are associated with a risk of developing secondary conditions that can be debilitating and even life-threatening (e.g. deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and

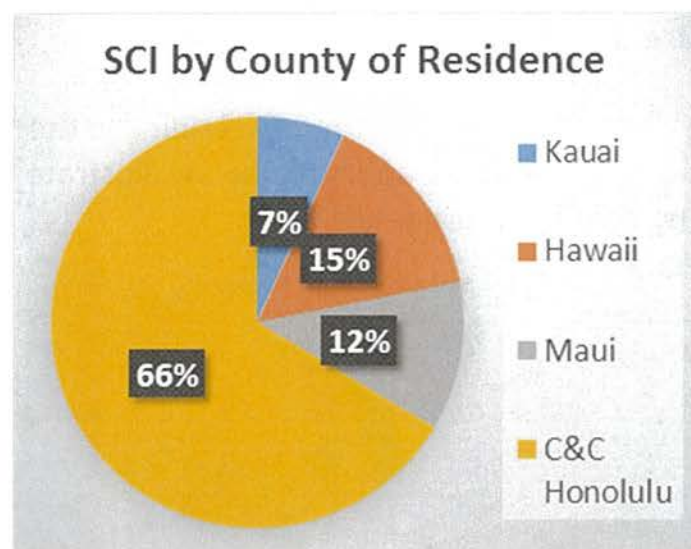


respiratory complications). Acute care, rehabilitation services and ongoing health maintenance are essential for prevention and management of these conditions. An estimated 20-30% of people with a spinal cord injury show clinically significant signs of depression. (World Health Organization, 2013).

The leading causes of spinal cord injury in Hawai'i from 2009-2013 were related to oceanic activities (33%) followed by falls (25%), motor vehicle crashes (22%), striking (5%), other sports (non-aquatic; 2%), water dives (non-ocean; 2%), assault (2%), bicycle crashes (2%), sky dive (1%) and other injuries (5%) (Department of Health, Injury Prevention and Control Section PowerPoint, 201:

<http://health.hawaii.gov/injuryprevention/files/2015/08/wsocon15a.pdf>).

Per the HHIC data, a total of 146 unique individuals currently residing in the State of Hawai'i were hospitalized for an SCI. The chart and table below illustrate the breakdown of SCI hospitalizations in 2015 by County of Residence.



County	Count
Kaua'i	10
Hawai'i	22
Maui	17
City & County of Honolulu	97
Total Hospitalizations in 2015	146

Source: HHIC (reflects data collected from 2015)

## Stroke

As mentioned in the introduction, stroke was included in the definition of neurotrauma because it is a preventable neurological dysfunction that can substantially limit a number of areas of functioning. Stroke is a disease that affects the arteries leading to and within the brain. There are two types of strokes: 1) ischemic stroke where clots can form in the brain's blood vessels, in blood vessels leading to the brain or even in blood vessels elsewhere in the body and then travel to



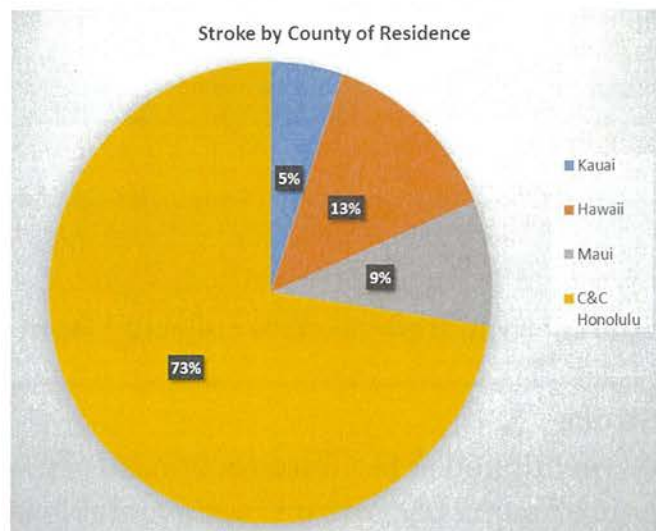
the brain blocking blood flow to the brain's cells. About 80% of all strokes are ischemic; and 2) hemorrhagic stroke which occurs when a blood vessel in the brain breaks or ruptures, resulting in blood seeping into the brain tissue, causing damage to brain cells. The most common causes of hemorrhagic stroke are high blood pressure and brain aneurysms.

The effects of a stroke depend on the location of the obstruction -- right brain versus left brain -- and the degree to which the brain is damaged. Following a stroke individuals may experience weakness or numbness of the face, arm, or leg on one side of the body; loss or diminished vision; difficulty with speech and language; loss of balance; and problems with memory. A stroke may cause long-term brain injury and physical disability.

In 2014, 3.1% of Hawai'i adults reported that a health care professional told them they had a stroke. The prevalence of stroke was highest among individuals of Japanese (4.2%) and Native Hawaiian (3.7%) ethnic background and increased with age (The Hawaii Health Data Warehouse, 2016).

Per HHIC data, in 2015 a total of 2392 unique individuals currently residing in the State of Hawai'i were hospitalized for stroke. The chart and table below illustrate the breakdown of stroke hospitalizations by County of Residence.

County	Count
Kaua'i	125
Hawai'i	319
Maui	211
City & County of Honolulu	1737
Total Hospitalizations in 2015	2392



Source: HHIC (reflects data collected from 2015)

### ***About Treatment of Neurotrauma***

An individual who sustains a neurotrauma injury is usually treated by emergency medical services (EMS) personnel at the scene or in the ED. Someone with moderate to severe neurotrauma will be admitted for acute care and rehabilitation. Once stabilized, the individual may be referred for additional rehabilitation to restore functioning and/or to acquire compensatory strategies to minimize physical, cognitive and behavioral deficits. Therapies may also assist with maintaining functioning over the long-term.

Supports for individuals include vocational rehabilitation to learn or re-learn job skills, counseling, a range of support groups and community services to assist in regaining functionality in order to reside in one's home, as well as in-home support, personal care, and assistance with activities of daily living.

The initial treatment and care may be paid by health care or auto insurance, workers' compensation, private pay, Medicaid, or Medicare. There may be limitations with regard to post-acute rehabilitation as to the extent of coverage. Health insurance usually does not pay for extensive rehabilitation, particularly residential rehabilitation, or long-term services and supports. Individuals with neurotrauma may seek governmental assistance for these types of services.

### ***About the Neurotrauma Supports Program and Resources in Hawai'i***

The Neurotrauma Supports program is housed in the Community Resources Branch of the Developmental Disabilities Division (DDD). Since 2002, DDD has been responsible for the NSF created by Act 160, to support individuals with neurotrauma and their families and for education, awareness and prevention of neurotrauma. As such, the Neurotrauma Supports program staff provide information and referral (I&R) services to assist individuals seeking services and resources through a Neurotrauma Helpline and resources posted on the DDD website.

The NSF budget is subject to the amount of revenue obtained from traffic related surcharges from traffic citations. The annual expenditure ceiling is \$1,038,992, which means the program cannot expend funds beyond this amount. Annual revenues via traffic citations are as follows:

- FY 2013: \$861,207
- FY 2014: \$801,742



- FY 2015: \$785,029
- FY 2016: \$784,351

To meet the mandate of the NSF legislation, the DDD Neurotrauma Supports program promotes public awareness through community events and conferences, particularly during March, which is National Brain Injury Awareness Month. The Neurotrauma Supports program also has awarded contracts to support projects to:

- Collect data through the voluntary registry;
- Promote public and professional concussion education and awareness statewide through presentations;
- Pilot baseline cognitive testing and a “return-to-play” protocol for public and private high school student-athletes who sustained a sports-related concussion through the Hawai’i Concussion Management and Awareness Program (HCAMP);
- Establish a Brain Injury Resource Center through the Brain Injury Association of Hawai’i (BIAHI); and
- Establish a statewide stroke network to improve statewide access to timely, expert stroke care evaluation and treatment under the coordination of the Queen’s Medical Center.

In 2012, Act 197, Relating to Concussions, was signed into law requiring the Department of Education and the Hawai’i High School Athletic Association to develop and provide a concussion awareness program. HCAMP, through a contract modification with the Neurotrauma Supports program in December 2012, fulfilled Act 197 by developing and incorporating an educational component in HCAMP.

In 2016, lawmakers expanded Act 197 by passing Act 262, Relating to Concussions, which mandates baseline cognitive testing for high school students and education/awareness to youth athletics. To fulfill Act 262, HCAMP continues to implement baseline cognitive testing for high school student-athletes, and the NSF plans to fund Project Head, Neck, Spine, which will educate elementary and middle school students on the signs and symptoms of head injuries and concussions, how to recognize possible neck and spinal cord injuries, and how to assist when someone sustains either a head, neck or spine injury. The project will utilize a web-based learning module for classroom teachers in the private and public schools to implement.



Individuals with neurotrauma may be eligible for other state services and resources, including services provided by the Division of Vocational Rehabilitation; Developmental Disabilities Division (DDD; for individuals who sustained a neurotrauma injury prior to age 22); Children with Special Health Needs Branch (Title V Maternal and Child Health Block Grant); Hawai'i Centers for Independent Living (CILs); state Medicaid program; and the Hawai'i Aging and Disability Resource Center (ADRC), which helps older adults, individuals with disabilities, and family caregivers find options for long-term supports and services available in Hawai'i.

The Assistive Technology Resource Centers of Hawai'i (ATRC) is the State's designated Assistive Technology Act agency, which links people with disabilities to technology and empowers individuals through its use. The Hawai'i Disability Rights Center promotes and advocates for human, civil, and legal rights of persons with disabilities and provides educational advocacy for students with disabilities. The Disability Rights Center receives federal funding for various advocacy components, including funding from the TBI Act to advocate on behalf of individuals with TBI.

In 1990, TBI was added as a category of disabilities eligible for special education and related conditions, provided other conditions are met. Children and youth with other disabilities related to a neurotrauma injury may be served under the other health impairment or multiple disabilities categories. The Special Parent Information Network (SPIN) is a parent to parent organization in Hawai'i that provides information, support and referral to parents of children and young adults with disabilities and the professionals who serve them.

There are also several private and nonprofit healthcare organizations, social services programs, universities, and other organizations that provide treatment and care, information, support groups, and other assistance to individuals with neurotrauma and their families. These entities may be represented on the Hawai'i Neurotrauma Advisory Board and the State Traumatic Brain Injury Board and also collaborate with the Neurotrauma Supports program.

### Section 3: Mission, Vision, Values and Guiding Principles

The mission, vision, and guiding principles of the Neurotrauma Supports program reflect those adopted by the Developmental Disabilities Division. The Strategic Plan was initiated to help carry out its mission:

**Mission:** Enhance partnerships to ensure individuals with neurotrauma and family members have access to services and supports.

**Vision:** Individuals with neurotrauma will have healthy and meaningful lives.

The Strategic Planning Committee concurred with the values and principles under which the program operates. That is, services, supports and assistance should reflect the individual's strengths, desires, interests, and goals. The individual should be an integral part of decision-making and empowered to self-direct care and supports.

#### Values

- ✓ Health and well-being of neurotrauma survivors and family members
- ✓ Dignity and respect for each individual
- ✓ Individual choice, control and responsibility
- ✓ Honoring diversity and human rights
- ✓ Personal growth and accomplishment

#### Guiding Principles

Service delivery system is:

- ✓ Accessible/available/flexible;
- ✓ Implemented through best practices;
- ✓ Innovative/creative;
- ✓ Accountable;
- ✓ Coordinated and seamless through partnerships;
- ✓ Person-centered; and
- ✓ Empowering the individual.



## Section 4: Strengths, Challenges and Opportunities

### ***Strengths***

A main strength of the Neurotrauma Supports program is that Hawai'i has a dedicated fund for neurotrauma. The NSF helps fill gaps and provide much needed information and resources to individuals with neurotrauma and their families. Two advisory boards support the program, bringing personal and professional experience together and representing neurotrauma-related issues across the lifespan. The program also has working relationships with non-government organizations and partners with these agencies to address service needs.

Hawai'i has the unique distinction of having one of the lowest uninsured rates in the nation (State Scorecard Report, 2015), although not all insurance plans cover extensive rehabilitation. Hawai'i also participates in Medicaid Expansion through the Affordable Care Act, which extends eligibility for Medicaid to adults with income up to 133 percent of the poverty level (138 percent with the automatic 5 percent income disregard).

### ***Challenges***

There are challenges at all levels in providing timely and coordinated services to meet individual needs due to the following: 1) resulting disabilities from neurotrauma vary, depending on numerous factors, and no two individuals with neurotrauma are alike; 2) system challenges in providing needed services that are partly due to varying eligibility requirements, a lack of experienced and trained professionals across the system, and a lack of funding; and 3) the geographic challenges of the state. In addition, Hawai'i is a culturally diverse state, and an understanding of the unique languages and social and cultural norms are required to adapt services to best meet the needs of the people of Hawai'i. Hawai'i's population is also aging, according to the Hawai'i State Plan on Aging (2015 - 2017), which will likely affect the incidence of strokes and fall-related TBIs because older adults are a high risk group.

Some of the challenges related to neurotrauma include the following:

- The resulting disability from neurotrauma is often invisible, yet the person may have problems with memory, thinking and other cognitive problems;
- Problems with mobility and activities of daily living; and



- Issues with co-occurring conditions, such as mental health and substance abuse issues.

The greater impact of neurotrauma is not always immediately known because cognitive and behavioral problems may surface many years later. Families, educators and employers may be assured that the individual has been initially successfully treated only to discover that over time, the individual may be unable to handle multiple tasks that are often required at school or on the job. The individual may be unable to organize his or her schedule or may experience difficulty with personal and/or social interactions. Health care providers will need to be informed of these potential health care conditions in order to appropriately treat an individual.

Individuals with neurotrauma are treated and cared for by multiple systems, each with its own purpose, mission, and eligibility requirements. Individuals may first seek treatment from a health care provider or hospital and then be discharged to home. In some cases, individuals are referred to a post-acute rehabilitation provider or individual therapists for additional speech-language, physical, occupational, and/or cognitive therapy. After a neurotrauma injury, individuals may need assistance at school or with returning to employment and may also require on-going assistance, such as counseling, support groups, and other community supports, to assist with recovery and live in the community. During this process, both the individual and the family may interact with health care systems, the education system, social programs, agencies for individuals with disabilities, and programs involving funding provided by private health or auto insurance, Workers' Compensation, the state, Medicaid, or other government programs.

Negotiating these entities and systems can be challenging for families because these groups often do not necessarily communicate or coordinate with each other unless a case manager/service coordinator, social worker, or advocate serves as a facilitator. The Strategic Planning Committee notes that post-acute rehabilitation is often not covered in insurance plans. Those that have coverage are referred to out-of-state programs due to lack of rehabilitation providers in Hawai'i.

Other challenges noted by the Strategic Planning Committee include Hawai'i's non-contiguous nature, geographic isolation, cultural diversity, and that supports and services tend to be O'ahu-centric with little or no resources (e.g., qualified healthcare providers, transportation), available for individuals and families on the neighbor

Islands. Committee members also believe there are an insufficient number of rehabilitation providers and professionals properly trained in neurotrauma to assist individuals.

### ***Opportunities***

The Neurotrauma Advisory Board (NTAB) and the State's Traumatic Brain Injury Advisory Board (STBIAB) provide opportunities for members to assist the Neurotrauma Supports program in identifying needs and to work collaboratively to improve the coordination of services and resources in order to make the system as seamless as possible for individuals with neurotrauma and their families.

The Neurotrauma Supports program has access to video conferencing which lends itself to offering training, education, and information to individuals with neurotrauma, families, and professionals living on O'ahu and neighbor islands. With technology, the program is able to feature national and state experts to provide periodic training. The program already supports web-based training to help educators to better understand concussion and neurotrauma.

In addition, many of the state programs have offices on the neighbor islands. Training may be provided through these agencies in order to reach out to those with neurotrauma who may be eligible for their services.

The Hawai'i Neurotrauma Registry identified the following needs as part of its preliminary analysis from the voluntary registry data, based on the responses from a statewide sample of 193 participants collected between 2013 to the present. The Neurotrauma Supports program hopes to gather a larger sample of registry participants to provide a more representative sample of the needs of survivors of neurotrauma in the State of Hawai'i. These needs represent opportunities to improve the statewide system of supports and services for individuals with neurotrauma and their families.

<b>All Islands</b>
Lack of social activities/groups (not formal support groups)
Lack of support groups for spinal cord injury survivors

Family members do not understand the aftermath of NT injuries (especially since most are discharged to home after injury)
Public does not understand the aftermath of neurotrauma injuries
Employers do not understand the aftermath of neurotrauma injuries
Few jobs/poor jobs for persons with neurotrauma injuries
Survivors of neurotrauma struggle to find and keep jobs
Lack of adequate finances
Lack of information
Problems with concentration, memory, forgetfulness
<b>O'ahu</b>
Lack of support groups for younger persons with neurotrauma injuries
<b>Neighbor Islands</b>
Lack of qualified physicians, which results in no care whatsoever or no continuity in care
Transportation
Not enough stroke and brain injury support groups

Source: Hawaii Neurotrauma Registry (2013-present).



## Section 5: Goals and Objectives

Individuals with neurotrauma and their families may need services and supports on a short-term, intermittent, or long-term basis. It is important to meet the challenge of identifying and coordinating available resources and services in order to provide the *right services at the right time*.

Individuals, families, and professionals identified these community-based short-term and long-term services and supports as the top priority. These services and supports need to be available on the neighbor islands, in addition to O'ahu:

- Support groups for both individuals and families (e.g., spinal cord, stroke)
- Opportunities for socialization
- Transition services/supports from hospital to home
- Behavioral supports
- In-home, personal care
- Respite for families and caregivers
- Education for individuals with neurotrauma/family
- Counseling
- Housing supports
- Post-acute rehabilitation, therapies to maintain functioning
- Assistance with activities of daily living
- Substance use treatment
- Service coordination/information on neurotrauma and available resources
- Transportation
- Employment and vocational rehabilitation
- Accommodations and related services to help with academic learning

Individuals with a mild neurotrauma may not seek treatment or be identified as having a neurotrauma injury, yet may develop symptoms later on or have changing needs and circumstances. Training educators, health care professionals, law enforcement, and other programs which provide education and services to older adults; victims of domestic violence; individuals with mental health conditions or substance use problems or both; individuals who are homeless; and veterans and returning service members to identify neurotrauma-related symptoms is critical in order to avoid misdiagnosis and to provide appropriate treatment, accommodations, and services.

<b>Goal 1: Expand public and professional awareness about neurotrauma and service delivery.</b>
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**Strategic Issue:** Understanding neurotrauma and resulting disabilities are essential in order for professionals to recognize, screen, assess, diagnose, and treat individuals accordingly. Individuals with neurotrauma and their families may seek assistance from medical, social services, education, and disability agencies which may have the type of services and supports needed, but to be effective, those involved in delivery need to understand the cognitive and behavioral issues associated with neurotrauma. Training caregivers to provide appropriate assistance has also been identified as a need. The public also needs to recognize the consequences of neurotrauma and resources available in order to know how to seek assistance for neurotrauma and assist an individual who may have sustained a neurotrauma injury.

**Objectives:**

**1.1** Identify partners and organizations (e.g., Brain Injury Association of Hawai'i, Hawai'i Disability Rights Center, Pacific Disabilities Center at the University of Hawai'i and the American Stroke Association) to promote neurotrauma awareness during various designated months (e.g. national spinal cord injury awareness month, stroke awareness month, brain injury awareness month, disability awareness month, disability employment awareness month).

**1.2** Expand presentations for community organizations and the public, featuring interviews with professionals in the field of neurotrauma and survivors of neurotrauma and their family members.

**1.3** Increase awareness and knowledge of neurotrauma and identification among disability and health care providers, including mental health; community health; health care agencies providing in-home supports or caregiver services; and substance abuse programs.

- Identify educational opportunities on neurotrauma for providers (e.g., training sessions, webinars, conferences, continuing education opportunities).
- Develop and maintain a network of providers to inform of educational opportunities on neurotrauma.



- Identify professionals in neurotrauma who are willing to mentor, consult, and/or offer peer support to professionals whose training is not in neurotrauma.

**Goal 2: Increase state's capacity to identify and disseminate information about resources, services, and supports to individuals with neurotrauma and their families.**

**Strategic Issue:** The neurotrauma registry is a resource for obtaining data to identify needs of individuals with neurotrauma and their families and to provide information and link individuals to resources and services. The Hawai'i Neurotrauma Registry, currently administered by a contractor, is a volunteer database funded by the NSF, therefore relying on self-reporting in order to obtain information necessary for follow-up. The sample currently includes a disproportionately higher number of older adults and a disproportionately lower number of children, younger adults, and individuals from neighbor islands.

Families and caregivers often wait until a crisis takes place before seeking help. Knowing and understanding available resources ahead of time may prevent crisis situations for both the individual and the family or caregiver. Increasing the number of those reporting registry information will allow more individuals to receive information.

### **Objectives:**

**2.1** Increase data reporting to obtain a more accurate assessment of the needs of individuals with neurotrauma and their family members through the neurotrauma registry.

- Identify methods to improve the appeal and feasibility of completing the registry needs assessment survey.
- Enhance the registry survey's focus on identifying the capacity of the services and supports currently available to address the needs of survivors of neurotrauma and family members.

**2.2** Expand capacity through existing disability and health care systems.

- Identify potential partners and providers (e.g. disability, public education, health care, mental health, community health centers, independent living centers, vocational rehabilitation) to refer for services and supports.
- Present information on neurotrauma during disability and health care conferences to encourage as many programs as possible to serve individuals with neurotrauma.

### 2.3 Identify funding mechanisms and opportunities for expanding capacity.

- Chart funding streams and eligibility requirements to determine potential sources of assistance for individuals with neurotrauma and their families.

**Goal 3: Identify strategies and partnerships to improve access to health care, rehabilitation, education, and community-based long-term services and supports and community integration for individuals with neurotrauma.**

**Strategic Issue:** Individuals, families and professionals have identified rehabilitation, and community-based short-term and long-term services and supports as the top priorities that need to be available on the neighbor islands, in addition to O’ahu. Individuals and their families often find barriers in accessing resources should such supports be available due to costs, transportation, and overall lack of resources specifically addressing the needs of individuals with neurotrauma. Collaboration and coordination of resources with similar disability and health care programs and providers may help to bridge the service delivery gap. Empowering persons to self-advocate through training may help individuals to identify their needs and to access services.

### Objectives:

**3.1** Research to identify and expand the database of services and supports currently available in order to link survivors of neurotrauma and family members to these resources (e.g., Aging and Disability Resource Center, SPIN, 2-1-1, etc.).

**3.2** Identify methods to access services and supports for individuals with neurotrauma who live on the neighbor islands (e.g., telehealth, support groups, mentorships, disability programs).



- Meet with potential providers to learn if individuals with neurotrauma may be eligible for their services, and if not, work with providers to identify ways to expand their services to individuals with neurotrauma.

**3.3** Identify opportunities for self-advocacy training to empower individuals with neurotrauma to access services to meet their needs.

- Collaborate with Hawai'i Disability Rights Center in providing self-advocacy training for individuals with neurotrauma.

## Section 6: Summary and Next Steps

### *In Summary*

The impact of neurotrauma varies with each individual, depending on factors such as the person's age at the time of the neurotrauma, pre-injury functioning, the severity of damage to the brain, neck or spinal cord, and access to timely rehabilitation and supports. Individuals may experience short-term issues or have life-long disabilities.

Hawai'i, like many states, does not have a sufficient number of providers, yet has opportunities to engage other disability and health care providers that are available to extend services and resources to individuals with neurotrauma and their families. Through training opportunities, these agencies and professionals may help fill in the service delivery gaps.

The Neurotrauma Advisory Board, the TBI Advisory Board and the Brain Injury Association of Hawai'i are valuable resources in providing the Neurotrauma Supports program with input on the needs of individuals with neurotrauma and their families. The membership of these entities also provides opportunities for expanding partnerships in order to expand capacity.

### Next Steps

The Neurotrauma Supports program will work with the Advisory Boards, other stakeholders and subsequent committees, which may be formed to address the goals of the plan and put forth a calendar for tackling the issues. Updates will be provided to the advisory boards during their meetings to keep members apprised of progress.